

**OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
November 23, 2021
Conference Call**

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Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 11/23/2021 to discuss the following agenda items:

1. Update on Section 2 – *Current/existing data on what patients want*
2. Discuss Section 1 – *Ethical justifications for transparency*

The following is a summary of the Workgroup’s discussions.

1. Update on Section 2 – *Current/existing data on what patients want*

A committee member utilized library services at the University of Wisconsin-Nebraska to pull literature based on set search terms. Members are still waiting for the results of this search to begin reviewing sources.

2. Discuss Section 1 – *Ethical justifications for transparency*

Members reviewed and discussed the draft text for the following sections:

Autonomy

A member suggested removing examples from this section since the future state section dives deeper into examples. The section author noted that the examples used in this section are used to illuminate the principles while the examples in the future state section would be more specific. A member suggested indicating the principles the workgroup used for selecting examples in the future state section. Ultimately, the group decided to remove the examples in this section and replace them with the episodes of care that are explained in the future state section. Members discussed the symbiotic relationship between the ethical principles of autonomy and transparency. UNOS staff suggested emphasizing the role of autonomy as a building block for transparency.

Equity

A member highlighted the fact that this section goes beyond just racial equity and identified other attributes that impact equity. UNOS staff inquired about ‘relatively powerless’ and if, from a patient perspective, this is the appropriate terminology to use. Members discussed alternative ways to illicit this point and suggested replacing the phrase with ‘marginalized.’

Utility

Members discussed how utility can differ between the patient perspective and the perspective of the transplant system. A member countered that although priorities may be different between the two stakeholders, there is still an agreed upon emphasis on efficiency and its benefit to both. UNOS staff

recommended addressing utility from both the patient and transplant center perspective and clarifying the commonalities between the two. Members discussed how they could use the same definition of utility and apply it across different levels. Ultimately, the group thought it was important to identify this potential conflict in utility but also acknowledge how they can support each other as well.

UNOS staff inquired if 'reducing patient complaints' accurately represented the point that was trying to be made in this section. Members suggested potentially replacing that language with 'increasing patient satisfaction.'

Procedural Justice

A member suggested that patients are owed an explanation as to why listing criteria exists. For example, it is not enough to know that a center has a body mass index (BMI) cut off but why the cut off is at the point and why another center may have a lower or higher BMI cut off. This statement does not need to be specific for each center, but instead included in a general manner with transplant metrics. The section author noted that this section will be similar to the autonomy section because they are both rooted in respect for persons.

Next steps:

The December workgroup meeting is cancelled. The workgroup chairs will be presenting its initial draft to the full Ethics Committee during their meeting on December 16.

Upcoming Meetings

- January 27, 2022
- February 24, 2022
- March 24, 2022
- April 28, 2022
- May 26, 2022
- June 23, 2022

Attendance

- **Workgroup Members**
 - Andy Flescher
 - Carrie Thiessen
 - Earnest Davis
 - Ehab Saad
 - George Bayliss
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Cole Fox
 - Kristina Hogan
 - Laura Schmitt
 - Susan Tlusty